Women, HIV Infection, and AIDS: Tapestries of Life, Death, and Empowerment

Michael Pizzi

Key Words: acquired immunodeficiency syndrome • health promotion • occupational science • occupational therapy

Women, the minority population in the human immunodeficiency virus (HIV) pandemic, are becoming one of the highest subgroups to be infected and affected by the disease. In the United States, most of these women are black or Hispanic, poor and urban dwellers, and addicted to drugs. This paper discusses the physical, psychological, and social manifestations of HIV disease in women, such as diminished activity tolerance, neurologic or cognitive changes, occupational and social role imbalance, and stigma and discrimination, and describes the sociocultural aspects of women's lives for assessment and treatment of women with HIV. Health promotion, education, and AIDS prevention and wellness programming are emphasized as strategies toward facilitation of self-empowerment for women with HIV disease. These health promotion and wellness strategies include learning of new and adaptation of current roles, learning strategies for self-care that include care for one's physical, psychosocial, spiritual, and sexual health, and learning and developing action plans toward healthy living and self-empowerment.

Prevalence and Transmission of HIV and AIDS

Between 1981, when the first cases of acquired immunodeficiency virus (AIDS) were discovered in the United States, and today, the number of women with human immunodeficiency virus (HIV) and AIDS has grown. In the 1980s, of an estimated 600,000 people worldwide who developed AIDS, 150,000 were women (Mann, 1989). It is estimated that more than 100,000 women in the United States are currently infected with HIV and that most of these women are unaware of their HIV status and lack any clinical medical manifestations (Centers for Disease Control, 1990b). The percentage of women with AIDS has grown from approximately 3.2% in 1981 to 11.5% in 1991 (Stoneburner, Chaisson, Weisfuse, & Thomas, 1990). It is projected that 80% of all newly diagnosed cases of AIDS will be heterosexually transmitted by the year 2000.

The incidence of AIDS is 10 times greater for blacks and 4 times greater for Hispanics than for whites. Black women account for 51.7% of women diagnosed with AIDS and Hispanic women make up an additional 20%. In the military, where recruits are routinely screened for HIV, for all age groups, rates of HIV infection are highest for black women (Miller, Turner, & Moses, 1990).

Transmission avenues for women with HIV and AIDS are diverse. Most transmission is through needle sharing from intravenous (IV) drug use (52%). Unprotected heterosexual contact is the second most frequent transmission mode (29%); such transmissions occur primarily through a partner who uses IV drugs and secondarily through a partner with hemophilia. Transfusion or blood components account for 13% of transmissions. Finally, 8% of diagnosed cases of women with AIDS have unidentified risk factors for HIV. Transmission may also occur via artificial insemination (Centers for Disease Control, 1990a). Among lesbians, the primary mode of transmission is IV drug use (Chu, Buchler, & Fleming, 1990).

Four factors associated with heterosexual spread of HIV are sexual behavior, sexually transmitted diseases (STDs), IV drug use and high-risk sexual behavior (unprotected sex) related to the exchange of sexual services for drugs (Holmes, Karon, & Kreiss, 1990). HIV is transmitted more easily from men to women than from women to men and women to women (Institute of Medicine, 1988).

Physical Aspects

For women, the spectrum of HIV-related infections and malignancies is similar to that of men, except that women are rarely diagnosed with Kaposi’s sarcoma (Wofsy, 1987). The infections include oral candidiasis, persistent fever and diarrhea, pneumocystis carinii pneumonia, cytomegalovirus, toxoplasmosis, tuberculosis, and mycobacterium avium. Other medical manifestations include pelvic inflammatory disease, chlamydia, vaginitis, and...
other STDs such as herpes and syphilis (Anderson, 1989). There may be peripheral and central nervous system damage including AIDS dementia complex, which is characterized by motor, cognitive, and behavioral dysfunction (Nava, Jordan, & Price, 1986). Fatigue, weakness, loss of coordination, balance, range of motion, and perceptual-motor dysfunction are often noted.

The conditions of women with HIV and AIDS, especially women of color and IV drug users, are often misdiagnosed or not diagnosed primarily because health professionals overlook gynecological infections associated with HIV (Benson & Maier, 1990). The human papillomavirus may be etiologically involved in the development of cervical dysplasia-neoplasia (Schafer, Friedmann, Mielke, Schwartzlender, & Koch, 1991). There is evidence that STDs are factors in HIV transmission. Anderson (1989) noted that patients with genital ulcerative disease are believed to have an HIV infection rate 3 to 5 times higher than that of patients with nonulcerative disease.

Psychosocial Aspects

"The sexism, cultural, socio-economic, abuse and health issues confronting minority women impact negatively on their motivation to learn and adopt risk reduction behaviors" (Bowden, James, & Meredith, 1989). Women with HIV share four unique characteristics:

1. a shorter life span than other groups, which leaves less time for planning their own lives and lives and custody of their children;
2. diagnosis-precipitated emotional chaos and shock, which may overwhelm the patient and her family;
3. presence of dependent minor children for whom crucial decisions must be made quickly; and
4. the nature and patterns of nontraditional but culturally specific familial relationships (e.g., large extended families) which, although strong, may present confusing and conflicting paths for outsiders to follow regarding the affairs of the patient and her children. (Kassel, 1991, pp. 227-228)

The woman with HIV undergoes tremendous psychological challenges, sometimes within a matter of moments, days, or weeks.

The negotiation of alternative sexual patterns is often a problem for women, especially those from ethnic minorities. Refusing sex or demanding use of condoms can mean loss of income if the woman is a prostitute or loss of housing and child care (Christ, Siegel, & M Modern, 1988). Negotiating alternatives in sexual contact carries the risk of loss of human contact, nurturance, and a sense of intimacy, especially for young women from abusive and nonnurturing environments who look for nurturing elsewhere. Additionally, many women feel that they must do as a man says in order to please and satisfy him so he will stay in the relationship, a relationship often based on dysfunction and co-dependency. "Chemically dependent women have low self-esteem, are not empowered, and are very much in traditional roles in their relationships with men" (Mitchell, 1990, p. 36).

Other psychosocial challenges arise around child-bearing. "Many women choose to have a child, risking their own and their child's life, for religious or cultural reasons or as a source of fulfillment; others choose abortion or to remain childless—sometimes a profound psychological challenge for women of childbearing age and male partners" (Christ, et al., 1988, p. 332). It must be noted that only one third of children born to mothers with HIV are themselves infected with HIV (Falloon, Eddy, Roper, & Pizzo, 1989).

Kassel (1991) noted that women who are HIV infected often need social and legal assistance and must plan for the medical care (and death) of their children and their significant others as well as for their own. These tasks are especially difficult because most women with HIV must also cope with the physical manifestations of the virus, including neurologic deficits, fatigue, pain, and altered mobility and occupational performance deficits. Stephens (1989) noted that for many of these women, IV drug use may directly or indirectly be a way of life; literacy may be diminished; separation from the dominant culture may occur on the basis of racial, ethnic, economic and religious differences; and access to health care may be limited.

Often, women with HIV who do not use IV drugs feel isolated and disconnected, and their feelings are compounded by the general public misperception of AIDS as an illness of gay men and IV drug users. They may avoid disclosing their status or seeking support for themselves for four primary reasons: (a) agreement with the societal perception that HIV does not really affect women and that AIDS agencies were created to serve the gay population; (b) fear of loss of custody of their children if their seropositive status were revealed; (c) historical relationship with health care and social services to the black and Hispanic communities, in which minorities distrust health care services and perceive them as unconcerned; and (d) lack of outreach to women by health care providers in general (Taylor-Brown, Williams, & Metzger, 1991).

Influence of Culture

Interventions by occupational therapists must be culturally sensitive to be most effective. Cultural issues and differences include family, intimacy, communication, and sexuality and gender roles that affect health promotion and wellness for the woman living with HIV. In the black culture, family structure includes extended, nuclear, and augmented families. Traditionally, all relatives are accepted regardless of circumstance. Religion and church are an important part of life. Although most blacks use modern health care, many still use faith healers, root doctors, and spiritualists (Wells, 1991). A large number of blacks live below the poverty level; a disproportionate number are women who are also heads of families. Because of this poverty, it has been suggested that black women who are IV drug users share needles more often than white IV
drug users and that their general health status is much lower (Peterson & Bakeman, 1989). Johnson (1991) suggested that problems for black women include inferior social and legal rights, little or no voice in sexual matters, and the added burden of serving as caregivers as well as managers of their families' daily needs.

The Hispanic culture is characterized by extended, nuclear, and female-headed family structures, but also by strong beliefs in family obligation and approval and male superiority. Many Hispanics are spiritual and can be heavily influenced by the Roman Catholic church; thus a Hispanic woman's ability to negotiate safer sex is often hindered by the church's disapproval of condom use. Hispanics can also be more present oriented than future oriented.

Hispanic culture treats health care providers as respected authorities and Hispanic patients usually prefer consistency in health care providers. However, direct communication with health care providers, especially if the providers' approach is negative or conflicts with cultural beliefs, may be avoided (Scaffa & Davis, 1990). A major barrier for Hispanic women is that their culture regards them as inferior to men and expects them to “suffer frustration and disappointment in silence, avoid losing face, and adjust to problems rather than solve them” (Wells, 1991, p. 18). Knowledge of cultural differences provide clues for health care providers to adapt services accordingly. Language can be a major barrier in the dissemination of AIDS information to Hispanic women. A woman may show agreement but not truly understand the message if it is not conveyed in her native tongue. Additional difficulties exist because the topics related to transmission of HIV—sex and drugs—are taboo topics in Hispanic culture. Effective presentation of health or AIDS information to this population emphasizes healthy living and wellness, avoids mentioning sex or drugs, and uses culturally sensitive graphics to enhance understanding.

Hispanic men, and many black men, are governed by the concept of machismo (e.g., being the one in control, the dominant one, the decision maker). This attitude often leads minority men to reject condom use. Because AIDS is increasing the fastest among these men, they unknowingly spread the disease to female partners (Matens, 1991). This fact must be considered when planning intervention or prevention efforts with women infected with HIV, with women at risk for HIV, or with a woman's family system. Matens (1991) explained that a machismo man needs to feel that he is in control of his life and that he has the responsibility to provide for his family. Therapists need to use this sense of machismo adaptively to help men deal with female partners with HIV.

Wells (1991) described several approaches that health care providers can use when working with minority women with HIV, including

Sociocultural Context of the Lives of Women With HIV

The daily reality of balancing roles and living with HIV and AIDS is often difficult. “Many women with AIDS simultaneously suffer from addictions and are from the most economically and educationally disadvantaged segment of our society. To short, to understand a woman with AIDS, one must understand the developmental, social, economic and cultural matrix of her life” (Wood & Aull, 1990, pp. 153–54). Maier (1986) described the lives of some of the women affected by HIV. They include a woman with AIDS who shared needles with her husband in 1981 without knowing the risk (and lost 3 infants to AIDS); a woman with AIDS who was a prostitute and shared needles with a female partner who has children; a woman with AIDS who had one sex partner 5 years after her divorce; and a woman with AIDS who returned to care for her dying, drug-using, abusive husband because “there was no one else to do it” (pp. 5–6). The struggle to survive becomes the predominant way of life for many of these women. Merzger (1977) aptly described this daily struggle: “Each day is a tapestry, threads of broccoli, promotion, colesh, children, politics, shopping, building, planting, thinking, interweaving in intimate connection with insistent cycles of birth, death, and existence” (p. 7).

Aptheker (1989) discussed the dailiness of women's lives or the patterns women create and the meanings they invent each day and over time as a result of their labors. Knowledge about a woman's dailiness is generated from those self-ascribed meanings. Aptheker stated that stories, or an oral tradition, can teach women self-respect, values, and ways to live properly and survive. From stories handed down through generations, the listener learns about the reality of a woman's life, “about the suffering, the failure, the struggle to nurture well... these reveal women's social conditions enforced by class, by race, by the prescription of gendered roles” (Aptheker, 1989, p. 40).

Women with HIV infection express an overt sense of helplessness, hopelessness, and lack of control. Many report a history of physical or sexual abuse and their sexual relationships include drug-related violence and illegal activity. Many women who inject drugs and are therefore at risk for HIV infection are poorly educated and depend on illegal sources of income or government programs for their livelihood (Sowder, Weismann, & Young, 1989). Carovano (1991) proposed a sociocultural
ly specific understanding of these women’s lives, behaviors, and life choices. She noted that women’s sexual identities are often defined by their reproductive capacity (as vessels that bear children) and, to a lesser degree, by involvement in commercial sex (prostitution). Both identity formations are based on relationship to others. “The focus on these particular identities, ‘mother’ and ‘prostitute,’ among the many that define women, leads one easily to the hypothesis that efforts to prevent AIDS among women have been the result, not of a concern for women, but rather a concern that is primarily about protecting the health of men and children” (p. 132).

Women have also been discriminated against in the health care system. They composed only 6% to 7% of 7,659 patients in antiviral drug clinical trials (“Inadequate Care,” 1991). Because they have shorter survival times than men, they are often excluded from the trials due to possible teratogenic effects of drugs. They were also not initially involved in testing the drugs thus far approved by the Food and Drug Administration, azidothymidine (AZT) and didoxycynosine (DDI); thus medication dosages and warnings of possible side effects for women can only be generalized from the population studied. The efforts of the Office of Research on Women’s Health at the National Institutes of Health (NIH) will change this discriminatory practice to include women in clinical trials.

Wolfsy (1987) asserted that women with HIV infection come from all walks of life and thus their issues cross all class, race, and cultural boundaries. These issues include profound grief for the loss of health, body image, sexuality, and childbearing potential; the burden of making decisions about initiation, continuation, and termination of pregnancy; the lack of natural community, such as that shared by gay men; the abruptness of diagnosis, which may be disclosed at the birth of an infected baby or death of a spouse; loss of self-esteem—feeling dirty, useless, unwanted and unlovable; the feeling of guilt from watching a child die; lack of male responsibility and the societal assumption that women have the responsibility for control of sex and conception.

Sociocultural examination of the dailiness of women’s lives promotes an understanding of the needs of women with HIV by providing a specific context from which health promotion and wellness strategies can be developed for each person. Their dailiness includes poverty, homelessness, and drug abuse. Crafted from the artifacts of daily living, the stories of these women evoke distinct meanings and distinct spatial and temporal arrangements. They can be used by the therapist to guide and facilitate self-empowerment.

Facilitating Self-Empowerment and Wellness: The Art and Science of Occupation

Given the diverse physical and psychosocial problems of women with HIV disease resulting in functional and occupa-
Occupational therapists facilitate self-empowerment and wellness through their specific skills. For example, they provide adaptive equipment for dressing independently or strategies for cooking a meal, involve people in stress management strategies, teach ways to negotiate safer sexual practices with significant others, teach proper nutrition and exercise regimens, and provide adaptive strategies for engaging in leisure and work roles. Provision of skills or tools so that one can control and master one’s environment despite living with a chronic illness such as HIV or AIDS is facilitating empowerment.

Occupational programming must be holistic and consider the sociocultural and historical context of a woman's life. Specific treatment approaches in wellness programming can be individual or group-oriented and can include developing or recreating role performance with respect to self-identified and valued roles; developing activity-centered routines and time management to enhance productive living and alternatives to substance abuse; developing self-esteem, self-worth, and self-empowerment through vital links with a woman's personal goals, dreams, and aspirations; and adapting parenting skills and nutrition and meal planning when appropriate (Pizzi, in press). Wellness must be defined by the patient herself. The therapist would then incorporate the woman's goals and needs into the treatment plan to facilitate her sense of control and wellness.

To best empower and instill hope for quality living in women who are already disenfranchised, therapists need to let go of biases and preconceived ideas of what capabilities others have or can develop. Creating programs, skills, and environments that are loving, nurturing, and supportive of a woman's choices will make the difference in the quality of living for that woman.

Self-empowerment programming may thus include development of rap or support groups where women can tell stories about living with HIV and AIDS, with the focus on setting goals toward wellness. Women in this group would work in pairs or triples to support each other's vision of personal wellness. Together, they would set their goals (e.g., this week I will stay clean [from drugs], not go hungry, play with my kids, take a shower daily, help a neighbor, discuss condom use with my boyfriend). They would coach and support each other toward goal achievement, with specific coaching meetings supervised, if requested, by the therapist, if the group felt more focus and direction was needed. The women would define how taking action toward healthy living is self-empowering.

Effective programming consists of listening to, acknowledging, and integrating the sociocultural and historical context of the lives of women with HIV. Facilitating self-empowerment and wellness for women with HIV and AIDS requires

- providing choices and options and allowing choice of life activity and adaptation
- training in adaptive technologies of self-care, work and leisure, and communication and interpersonal skill building
- supporting and developing the power to say no to poverty, homelessness, victimization, and illness
- developing plans of action to promote health and healing
- being sensitive to cultural and gender issues related to self, other, and HIV
- developing community support, support groups, and strategies for outreach to women
- developing positive images of self to engender a fighting spirit and to get on with life and living, not death and dying
- creating daily meaning with consideration of personal values and choices.

Summary

The intention of this paper was to introduce the myriad concerns, problems, and needs of women with HIV. When women are examined from a sociocultural perspective, therapists can more easily determine a woman's occupational roles and occupations of daily living that have self-ascribed meanings unique to that woman. Physical and psychosocial aspects of care must be understood in that sociocultural context and in the context of one's environment. Wellness, not illness, parameters most effectively guide treatment so occupational therapists can facilitate empowerment of women with HIV. Therapists most effectively facilitate empowerment through ethical, nonjudgmental, caring service. ▲

Acknowledgments

I gratefully acknowledge the contributions and inspiration of Mary Lou Galantino, Karen Stary, Margaret Provine, Allyson Mizenko, and the many women with HIV/AIDS I have been privileged to serve who helped shape this article.

References


Related Readings


Free publications on women and AIDS, including updated bibliographies from NOVA Research Company, 4600 East-West Highway, Suite 706, Bethesda, MD, 20814.

Free slides and publications with updated AIDS information from the Centers for Disease Control, 1600 Clifton Road, Atlanta, Georgia 30333.

---

**1992-1993 Educational Opportunities**

**A Saunders Group Company**

**Evaluation, Treatment and Prevention of Spinal Disorders**
Presented by
H. Duane Saunders, M.S., P.T.
Dallas, TX .......... November 6-8
Miami, FL ........... December 4-6
Durham, NC .......... January 23-26
Houston, TX .......... February 5-7
Detroit, MI .......... February 19-21

**Industrial Back Injury**
**Prevention and Management**
Presented by
H. Duane Saunders, M.S., P.T.
Anaheim, CA .......... November 13
San Francisco, CA .... January 28
St. Louis, MO .......... February 11

**Basic Spinal Mobilization**
Presented by
Daniel T. Wolfe, G.D.M.T, P.T.
New York, NY .......... November 7, 8
Pittsburgh, PA .......... January 16, 17
Boston, MA .......... February 6-7

**Cervical Spine & Shoulders**
Presented by
David A. Groom, G.D.M.T., P.T.
Seattle, WA .......... February 19-21
Minneapolis, MN .... February 26-28

**Reducing Injuries in the Workplace**
Presented by
Mark A. Anderson, M.A., P.T,
Mark R. Stultz, M.S.I.E., P.T.
and Skip Olson, P.T.
Dallas, TX .......... November 19-21
Memphis, TN .......... February 11-13

---

The American journal of Occupational Therapy